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## **Cover Page Footnote**

He gratefully acknowledges the assistance of Mitchell Holtzman in the preparation of this essay, and wishes to thank the following individuals for their helpful comments and suggestions: David Barr, Ronald Bayer, George Chauncey, Ruth Finkelstein, Geoffrey Knox, Stanley Kurtz, Jeff Levi, Carol Levine, Michael Musheno, David Rogers, William Rubenstein and Tim Sweeney.

# HIV AND THE NEED FOR A VOLUNTARIST APPROACH

David A. Hansell, Esq.\*

## I. Introduction

In this tenth year of the AIDS epidemic,<sup>1</sup> evidence abounds that we have reached a certain high water mark in the public consensus on how we as a nation should respond to the HIV crisis. Public opinion polls tell us that Americans have come to understand how little risk AIDS poses in everyday experience, and overwhelmingly profess sympathy rather than condemnation for people with AIDS.<sup>2</sup> Yet these attitudes often fail to translate into enlightened public policy. Instead, we have been consumed with battles over strident and medically unjustified demands for mandatory AIDS testing and removal from practice of HIV-infected health-care workers.<sup>3</sup> We have seen more and more states adopting legislation calling for forced testing of HIV-infected individuals in certain circumstances, or creating criminal penalties that stem from the status of HIV infection.<sup>4</sup> The resur-

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1. See Steven Eisenstat, *An Analysis Of The Rationality Of Mandatory Testing For The HIV Antibody: Balancing The Governmental Public Health Interests With The Individual's Privacy Interest*, 52 U. PITT. L. REV. 327, 327 ("Human Immunodeficiency Virus ('HIV') was first identified as the cause of Acquired Immunodeficiency Syndrome ('AIDS') in 1983").

2. See, e.g., THE ROPER ORGANIZATION, AIDS: PUBLIC ATTITUDES AND EDUCATION NEEDS (1991). In this nationwide poll, the vast majority of respondents indicated an understanding that AIDS could not be transmitted through casual contact, and 90% agreed with the statement: "Regardless of who has AIDS, they deserve our compassion." *Id.* at 13.

3. The revelation by the Centers for Disease Control of an apparent case of HIV transmission in a dental practice in Florida led to a widespread public debate over the risks of HIV infection faced by patients in medical and dental settings. This debate was played out in the media, in Congress and state legislatures, and culminated in the issuance by the Centers for Disease Control of practice guidelines for HIV-infected doctors and dentists. See *Recommendations for Preventing Transmission of Human Immunodeficiency Virus and Hepatitis B Virus to Patients During Exposure-Prone Invasive Procedures*, 40 MORBIDITY AND MORTALITY WEEKLY REP. RR-8, at 5-6 (1991) [hereinafter *CDC Recommendations*].

4. See David A. Hansell, *HIV Antibody Testing: Public Health Issues, in AIDS*

gence of tuberculosis in parts of the United States,<sup>5</sup> affecting those who are both HIV-positive and -negative, threatens to renew calls for isolation and quarantine measures. Steps like these represent draconian responses where sensitivity is needed, and suggest a futile desire to identify quick fixes for an extremely complex problem.

After a decade of fighting AIDS, the public health community has come to recognize that strategies to combat the infection must be premised on voluntarism and not on coercion. This belief is grounded on a recognition that AIDS is fundamentally different from other sexually transmitted diseases. Attempts to combat AIDS with coercive public health strategies stem from a desire to force AIDS into an ill-fitting traditional disease-response framework, overlooking the differences between HIV and other sexually transmitted diseases, including the limitations in available treatment modalities for HIV. A return to such a cramped, narrowly-medicalized view of the AIDS epidemic has enormous social implications and a coercive strategy would frustrate efforts to stem the spread of the disease. Further, such strategies would hamper the willingness of those in need of medical care and education to benefit from existing programs. This essay explores some of the possible explanations for the apparent erosion of the voluntarist consensus and calls for a return to such a voluntarist approach through effective health care and education efforts.

It is important to note that the perspective reflected in this essay is that of an organization that provides services to people with AIDS and HIV infection in the hardest-hit metropolitan area in the nation.<sup>6</sup> Gay Men's Health Crisis ("GMHC"), founded in 1982, has assisted more than 12,000 clients needing emotional and practical support, legal assistance, financial advocacy, meals and nutritional counseling and other services. GMHC has been a leader in the area of HIV prevention, offering educational materials, information and intensive safer sex programs to hundreds of thousands of people at risk. The views expressed herein are rooted in the agency's philosophy that its most important goals are to empower people with the knowledge and skills to live with AIDS, and to live in a world where AIDS will be a reality for a long time to come.

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PRACTICE MANUAL — A LEGAL AND EDUCATIONAL GUIDE (Paul Albert et al. eds., 1991).

5. See, e.g., Elisabeth Rosenthal, *Doctors Warn of a Looming TB Threat*, N.Y. TIMES, Nov. 16, 1991, at 22.

6. See Mary Arrigo, *Health-care Givers Mustn't Dodge AIDS*, N.Y. NEWSDAY, Mar. 18, 1992, at 89 (interview with Rose Walton) ("New York State has the highest number of cases of AIDS of any state and NYC has the highest of any city").

## II. The Realities of the AIDS Epidemic

The movement toward coercive strategies to combat AIDS is rooted largely in public fear and misunderstanding. The public panic over contracting HIV in the surgical suite or the dental chair, for example, reflects continuing, deep-seated misunderstandings about the disease.<sup>7</sup> In contrast, the voluntarist consensus is based on the realities of the HIV virus, whom it affects and the limited therapeutic interventions that are currently available. The voluntarist consensus recognizes that persons at risk of HIV infection can best be reached through a strategy that seeks their cooperation rather than one that attempts to mandate it.

### A. The People At Highest Risk for AIDS

The overlapping communities at highest risk for HIV infection are gay and bisexual men, men and women of color and intravenous drug users.<sup>8</sup> These groups have historically been suspicious of the public health establishment or unable to benefit from the existing services. To understand their suspicion, one need only recall that for decades homosexuality was treated as a psychopathology to be cured, or the infamy of the Tuskegee experiment.<sup>9</sup> Because the groups most impacted by the AIDS virus are wary of the public health establishment, coercive strategies to combat the disease will only intensify their distrust. In short, coercive measures that might succeed in a less charged environment are destined to fail when dealing with such disenfranchised populations.

### B. The Limited Treatment Options for AIDS

The only conditions that could arguably justify using compulsory strategies to combat an infectious disease do not exist in the AIDS arena. To date, despite significant progress, only limited treatment options for people with HIV exist in the medical community. These treatments do not offer anything approaching a "magic bullet" intervention that would justify coercive or nonconsensual attempts to identify and treat infected individuals. Similarly, existing therapeutic interventions have not been shown to reduce infectivity. Hence, mandatory steps to identify infected individuals will not help to stem

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7. See Larry Gostin, *A Decade of a Maturing Epidemic: An Assessment and Directions for Future Public Policy*, XVI AM. J.L. & MED. 1, 19 (1990).

8. See *AIDS and Human Immunodeficiency Virus Infection in the United States: 1988 Update*, 38 MORBIDITY AND MORTALITY WEEKLY REP. 7, 17 (Supp. S-4) (1989).

9. See JAMES H. JONES, *BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT* (1981).

the spread of the virus. Risk-reduction education for all affected communities is the only effective means of furthering the goal of preventing new infections. Targeting only individuals who are already infected with HIV is an inadequate response to a pervasive epidemic about which both the infected and the uninfected need to be educated.

Finally, because HIV cannot be transmitted through casual contact, there is no need for a public health strategy that seeks to identify infected individuals who may unknowingly spread the disease. In fact, public identification of infected individuals would do much to discourage those in need from seeking treatment. Again, the only effective intervention is to educate all populations at risk about modes of, and barriers to, HIV transmission.

Thus, the goal of HIV intervention, unlike intervention in relation to other sexually transmitted disease epidemics, cannot be encapsulated into the relatively simple objectives of identifying those infected and providing time-limited, curative treatment. Controlling HIV demands much more complex strategies geared not only toward treating existing cases, but also toward educating the population about preventive measures.

### III. The Goals of the Public Health Response to AIDS

The public health response to AIDS, in order to be successful, must be capable of meeting two goals. First, medical care must be made available to those in need. Second, the educational measures that foster long-term behavioral changes that can stem the spread of the disease must be implemented. There are substantial barriers, however, to achieving both of these goals.

#### A. Providing Medical Treatment

Persons who are HIV-infected should be continuously monitored for immune impairment, and should have access, as early as necessary, to prophylactic treatment to maintain their immune response and their overall medical condition.<sup>10</sup> The adjustment to long-term pharmacological maintenance may not be easy, but at present it provides the best hope for preserving the health of HIV-infected individuals.<sup>11</sup> Furthermore, the promise of accessible, adequate and affordable medical treatment is the best incentive for people at risk to

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10. See Peter S. Arno, et al., *Economic and Policy Implications of Early Intervention in HIV Disease*, 262 JAMA 1493, 1496 (1989).

11. *Id.*

come forward, to learn their HIV status and, in the process, to receive counseling about risk reduction and transmission prevention.

The United States health-care delivery system is incapable of providing medical treatment, with any degree of assurance, to the hundreds of thousands of infected and immune-compromised individuals who need such care. Between thirty-one million and thirty-six million Americans lack any health insurance,<sup>12</sup> and millions more are inadequately insured.<sup>13</sup> The annual cost of a standard prophylactic regimen for asymptomatic HIV infection totals roughly \$10,000 per person.<sup>14</sup> Without comprehensive insurance, the cost of care is far beyond the reach of all but the wealthiest members of our society.

The Medicaid program also fails to provide the necessary care. Although the primary means of health insurance for the poor, Medicaid fails to cover millions of people below the poverty level.<sup>15</sup> Further, federal Medicaid provisions do not require that the individual state administrators of Medicaid cover immune-compromised individuals who fail to meet standards for physical disability.<sup>16</sup> Hundreds of thousands of asymptomatic individuals with the HIV virus do not qualify for Medicaid coverage. Even those who do qualify for Medicaid generally receive only minimal care, with reimbursement rates so low that many, if not most, physicians in heavily impacted areas refuse to participate in the program.<sup>17</sup> Thus, the objective of delivering medical treatment to all HIV-infected individuals in need of care is undercut by serious inadequacies in the U.S. health-care delivery system.

## B. Providing Education

A second overriding objective of the voluntarist consensus is to ed-

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12. See Emily Friedman, *The Uninsured: From Dilemma to Crisis*, 265 JAMA 2491, 2491 (1991).

13. *Id.* at 2492.

14. See Arno, *supra* note 10, at 1497.

15. Medicaid coverage most often accompanies a determination of eligibility for federal Supplemental Security Income (SSI) benefits, which requires that an individual be aged, blind or disabled, or Aid to Families with Dependent Children benefits, which require membership in such a family. Indigence and need for medical care alone do not qualify one for Medicaid under federal mandates. See 42 U.S.C. § 1396a(e) (1989).

16. For the past few years, legislation has been proposed in Congress to authorize states to offer Medicaid coverage of certain HIV-related services (principally prophylactic drug therapy) to indigent individuals with HIV infection who are significantly immune-suppressed. See, e.g., H.R. 1394, 102nd Cong., 1st Sess. (1991) These individuals would generally not qualify for Medicaid under existing federal standards. See 42 U.S.C. § 1396a(a) (1989).

17. Jesse Green & Peter S. Arno, *The 'Medicaidization' of AIDS: Trends in the Financing of HIV-Related Medical Care*, 264 JAMA 1261, 1261 (1990).

ucate persons at risk for HIV infection. These people must be reached with techniques that have the capability to effect profound, continuous and sustainable behavioral change. It is a formidable public health education challenge to teach people to modify lifestyles that include unsafe sexual or drug-using behavior. It is an even greater challenge to create long-lasting behavioral changes.

Efforts to bring about long-term behavioral modification have met with little success. Congress and the federal agencies responsible for AIDS education funding have thwarted practical education efforts to protect high risk communities and others. Public health agencies and private organizations have been discouraged from instructing gay men how to have sex safely, or drug users how to use needles safely, and have risked losing their federal funds if they do so. In May 1992, a federal court struck down a set of grant requirements imposed on the content of AIDS educational materials by the Centers for Disease Control ("CDC").<sup>18</sup> These requirements, promulgated in 1988, required that materials produced with federal funds use language that "would be judged by a reasonable person to be inoffensive to most educated adults" beyond the target audience.<sup>19</sup> The court held that this requirement was unconstitutionally vague and exceeded the CDC's statutory authority.<sup>20</sup>

No strategy for responding to HIV will succeed unless it takes as a fundamental premise that long-term behavioral change, not short-term intervention, is required. Strategies that look solely toward tracing of infected individuals and treatments that can interrupt the chain of infection are inapplicable in the context of HIV. Coercive strategies ignore the cooperation necessary to achieve the long-term behavior modifications and to grapple with the HIV epidemic. Routine or mandatory HIV screening programs violate the voluntarist consensus. Such programs consume substantial resources, achieve little public health benefit and jeopardize cooperative efforts that can control the

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18. *Gay Men's Health Crisis v. Sullivan*, No. 88 Civ. 7482 (May 11, 1992). This action, filed in 1988, challenged the so-called Helms Amendment, adopted by Congress in 1987, which stated that no funds from Centers for Disease Control "shall be used to provide AIDS education, information or prevention materials or activities that promote or encourage, directly, homosexuality." Continuing Appropriations Bill for Fiscal Year 1988, Pub. L. No. 100-202, § 514(a), 101 Stat. 1329, 1329-289 (1987). This language was incorporated into guidelines for recipients of federal AIDS prevention funds, which were also challenged in the litigation. Content of AIDS-related Written Material, Pictorials, Audiovisuals, Questionnaires, Survey Instruments, and Educational Sessions, 53 Fed. Reg. 6034 (1988) [hereinafter CDC Guidelines].

19. 53 Fed. Reg. 6034.

20. *Gay Men's Health Crisis v. Sullivan*, No. 88 Civ. 7482 (May 11, 1992) at 63.



epidemic.<sup>21</sup>

Identification per se of HIV-infected individuals through routine screening programs accomplishes nothing, and does not serve the goals of risk reduction education or referral of those who are infected to appropriate treatment. In an extreme example, a premarital HIV screening program enacted (and quickly abandoned) in Illinois drove thousands of couples out of the state to get married, and cost the state \$312,000 per seropositive test result, hardly a judicious use of public resources.<sup>22</sup>

#### IV. The Voluntarist Approach

The voluntarist consensus takes these factors into account, and seeks to combat the AIDS epidemic by encouraging participation from those people at risk for the disease. The voluntarist consensus is rooted in a belief that cooperative strategies to combat AIDS are more practically effective, as well as ethically and constitutionally palatable, than coercive strategies. The voluntarist consensus, therefore, has as its main goal voluntary HIV testing, accompanied by appropriate pre- and post-test counseling. Voluntary HIV testing can serve as the gateway to medical treatment and educational programs available to high-risk populations.

##### A. Voluntary HIV Testing

Voluntary in this context means that HIV testing is undertaken only with the fully informed consent of the subject. Informed consent must include an explanation of the HIV antibody test and its meaning, the availability of treatment for HIV infection, the potential psychological and social ramifications of being diagnosed as HIV-positive, and the limits to confidentiality of HIV-related information as provided by relevant state law.<sup>23</sup> Without such a process, the educational value of testing will not be realized, and the individual contemplating testing will be denied the opportunity to make a voluntary, autonomous decision.

Voluntarism further demands that the confidentiality of those seeking testing be fully protected, and that testing on an anonymous basis be available as an alternative to testing by name in the medical setting. Reporting to governmental authorities the identities of individuals

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21. INSTITUTE OF MEDICINE, NATIONAL ACADEMY OF SCIENCES, *CONFRONTING AIDS: UPDATE 1988*, at 75.

22. Bernard J. Turnock & Chester J. Kelly, *Mandatory Premarital Testing for Human Immunodeficiency Virus: The Illinois Experience*, 261 JAMA 3415, 3415 (1989).

23. INSTITUTE OF MEDICINE, *supra* note 21, at 72.

who are HIV-infected will discourage people at risk from coming forward for counseling, testing and treatment. Similarly, societal discrimination against persons with HIV infection must end so that they can make medically-driven decisions to seek testing and treatment without risking adverse personal consequences.

### B. AIDS Education Programs

Since HIV is transmitted by specific, controllable behaviors for the most part,<sup>24</sup> the voluntarist consensus holds that giving people at risk the knowledge and the tools to effect long-term behavioral change is the best way to reduce transmission. Such educational methods serve a dual purpose: they not only teach infected persons how to avoid spreading the virus, but they also teach uninfected members of the same at-risk communities how to avoid being infected, since every unsafe activity poses reciprocal risks to both participants.

Meaningful AIDS education, however, requires a relationship of trust and confidence, particularly as it must deal frankly with such sensitive issues as sexuality and drug use. Furthermore, any educational program, particularly one whose goal is behavioral change, is effective only to the extent that it rests upon a desire to incorporate and act upon the information being shared. Coercive programs are unlikely to create the motivation needed for AIDS education to be successful.

### V. The Erosion of the Voluntary Consensus

The consensus that has developed around these voluntary strategies is quite remarkable. The National Academy of Sciences, the President's Commission on the HIV Epidemic, the National Commission on AIDS, and most components of the professional public health community agree that a voluntarist approach has merit.<sup>25</sup>

There even seems to be symbolic judicial support for voluntary strategies. The New York State Court of Appeals recently upheld a state health department's decision to treat AIDS along voluntarist lines and hence differently from other contagious or sexually transmitted diseases.<sup>26</sup> This decision constitutes the first state high court

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24. Nancy Mueller, *The Epidemiology of the Human Immunodeficiency Virus Infection*, 14 LAW MED. & HEALTH CARE 250, 256 (1986).

25. INSTITUTE OF MEDICINE, *supra* note 21; REPORT OF THE PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC (1988); AMERICA LIVING WITH AIDS: REPORT OF THE NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME (1991).

26. *New York Soc'y of Surgeons v. Axelrod*, 77 N.Y.2d 677, 569 N.Y.S.2d 922 (1991) (upholding a determination of Commissioner of Health and State Public Health Council

ruling on the voluntarist issue. The development is particularly significant coming from the state most heavily affected by the HIV epidemic.<sup>27</sup>

Despite these strong signs of support for the voluntary consensus, there are clear and definite signs that this consensus is eroding and being replaced with a coercive ideology. Developments within the medical community and the government itself do not bode well for the voluntarist strategy.

#### A. Erosion in the Medical Community

In early June, 1991, only three weeks after the New York Court of Appeals decision, an editorial in the prestigious *New England Journal of Medicine* called for a complete, indeed breathtaking, rollback of the entire voluntarist strategy.<sup>28</sup> In no more than a few paragraphs and with virtually no analysis or substantiation, the *New England Journal* article endorsed routine testing of all health-care workers and patients, systematic tracing of the sexual partners of HIV-infected persons, and routine screening of all pregnant women and newborns.<sup>29</sup>

Significantly, the *New England Journal* article addressed a medical strategy for the HIV epidemic by divorcing it completely from its social context. It suggested a so-called "dual approach" to AIDS, one that "attempts to distinguish social from epidemiologic problems and that deals with both, simultaneously but separately."<sup>30</sup> In other words, the article argued, concerns about discrimination and access to treatment must be resolved, but these factors should not impinge on the medical response to the epidemic, which should proceed along traditional, coercive public health lines.

#### B. Erosion in the Government

In the summer of 1991, the United States government reinforced its existing policy of barring HIV-infected individuals from gaining naturalization or immigration status in the United States. Visitors, immigrants, and applicants for permanent residency would continue to be subject to HIV testing as a potential bar to entry into the United

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not to add HIV infection to lists of communicable and sexually transmissible diseases, based on concern that mandatory testing and contact tracing would prevent infected persons from cooperating with public health officials).

27. See Arrigo, *supra* note 6.

28. Marcia Angell, *A Dual Approach to the AIDS Epidemic*, 324 *NEW ENG. J. MED.* 1498, 1498-1500 (1991).

29. *Id.* at 1499.

30. *Id.*

States.<sup>31</sup> HIV was originally added to the list of excludable conditions in 1987 at the direction of Congress.<sup>32</sup> Although Congress removed this mandate in 1990,<sup>33</sup> The Immigration and Naturalization Service has to date retained the HIV exclusion. This has the impact of driving HIV-infected immigrants underground, away from counseling and health care, because of the reality or the fear that identification of their HIV status could jeopardize their continued residence in the United States.

Next, in early July, the Centers for Disease Control ("CDC") issued guidelines prohibiting HIV-infected health-care workers from engaging in certain forms of medical practice, despite a level of risk to patients that, by the CDC's own estimates, is minute.<sup>34</sup> Two days later, the United States Senate overwhelmingly adopted two measures, one to brand as criminals HIV-infected physicians who perform "invasive" procedures without informing patients of their HIV status,<sup>35</sup> and a second to require that the recently promulgated CDC guidelines be implemented in every state in the country.<sup>36</sup>

While this dramatic and disturbing series of events occurred within a matter of weeks, other currents had been pushing in the direction of coercive HIV strategies for some time. Beginning in 1987, more and more states adopted legislation requiring mandatory name reporting of cases of HIV infection,<sup>37</sup> and the CDC, quietly at first but gradually more openly, supported that approach.<sup>38</sup> Many states passed laws calling for forced HIV testing of persons suspected or convicted of sexual assault, or of persons who may have exposed health-care or emergency response workers to HIV.<sup>39</sup> While many of these laws

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31. Public Health Service, Interim Rule: Medical Examination of Aliens, 56 Fed. Reg. 25,000 (May 31, 1991).

32. Supplemental Appropriations Act of 1987, Pub. L. No. 100-71, § 518, 101 Stat. 391, 475 (1987).

33. 8 U.S.C. § 1182(a), as amended by the Immigration Act of 1990, Pub. L. No. 101-649, § 601, 104 Stat. 4978, 5067 (1990).

34. The CDC estimated that the risk of HIV transmission from an infected health care worker to a patient is 2.4 to 24 per 1,000,000 medical procedures. CENTERS FOR DISEASE CONTROL, ESTIMATES OF THE RISK OF ENDEMIC TRANSMISSION OF HBV AND HIV TO PATIENTS BY THE PERCUTANEOUS ROUTE DURING INVASIVE SURGICAL AND DENTAL PROCEDURES (Jan. 30, 1991).

35. 137 CONG. REC. S11,792 (1991).

36. 137 CONG. REC. S10,1032 (1991).

37. Hansell, *supra* note 4, at 3-12.

38. *Update: public health surveillance for HIV infection—United States, 1989 and 1990*, 39 MORBIDITY & MORTALITY WEEKLY REP. 853, 861 (1990).

39. See Hansell, *supra* note 4, at 3-7, 3-8. See, e.g., COLO. REV. STAT. § 25-4-1402(1), (2) (1989); S.C. CODE ANN. §§ 44-29-10 (Law. Co-op. 1989).

were passed in states with very low HIV incidence,<sup>40</sup> they nevertheless reflected a trend that ran counter to the prevailing voluntarist consensus.

## VI. Reasons For the Erosion of the Voluntarist Consensus

A new term has recently entered the AIDS lexicon: HIV exceptionalism.<sup>41</sup> This term presages a new trend in public health thinking. It connotes a public health strategy that calls for different measures in response to AIDS than have traditionally been employed in responding to other sexually transmitted diseases. Yet acknowledging only the "exceptional" response to HIV alone ignores the greater reality. HIV itself is exceptional. It is exceptional in terms of the course of the infection as compared to other sexually transmitted diseases; it is exceptional in its mortality rates; it is exceptional in the stigma and discrimination that it engenders; and it is exceptional in its capacity to seek out marginalized populations that have long received a disproportionately small allocation of public resources. This more expansive definition of HIV exceptionalism should be considered in terms of the public health response. While it is true that HIV is an exceptional disease, to so characterize the public health response to HIV signifies an important and disturbing shift in the way that HIV has come to be perceived.

This shift indicates a departure from the earlier response of the public health community. Although there are no simple answers as to the validity of the movement away from the voluntarist approach, there are some explanations for this change of strategy. Some of the factors causing this shift in opinion are improvements in treatment for the HIV disease; the concentration of disease in specific, disenfranchised sectors of society and the changing public perception of the threat of HIV infection.

### A. Improvements in Treatment for HIV Disease

Perhaps the pivotal issue affecting the voluntarist-coercive debate has been the improvement of treatment options for HIV-infected, asymptomatic individuals. Though far from the stage at which symptomatic HIV disease can be held at bay indefinitely, medical science now offers interventions with clear benefits for those with impaired

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40. CENTERS FOR DISEASE CONTROL, HIV/AIDS SURVEILLANCE REPORT 5 (Apr. 1991).

41. Ronald Bayer, *Public Health Policy and the AIDS Epidemic — an End to HIV Exceptionalism?*, 324 NEW ENG. J. MED. 1500, 1500 (1991).

but still functioning immune systems.<sup>42</sup> Early knowledge of HIV status has thus become important as the trigger for prophylactic treatment regimens.

The response to these developments has been schizophrenic. One might well have expected that they would further bolster the voluntarist view. Against the pre-existing social backdrop, which strongly militates in favor of a scheme based upon individual, autonomous decision making, has been added a powerful incentive for persons at risk to opt for testing: the promise of life-extending (if not curative) treatment. This incentive would seem to dictate a framework that looks to voluntary choice as its touchstone. Educating people about treatment advances, protecting them from breaches of confidentiality and discrimination, and creating systems to deliver treatment to those who need it are methods by which the voluntarist approach could be fully implemented. Additionally, a powerful program for encouraging entrance to the public health system, even for those at-risk communities otherwise skeptical of it, would round out a voluntarist strategy.

The debate has not generally advanced in this direction. To traditional public health practitioners, the more HIV-related treatment improves, the more the disease begins to look just like any other sexually transmitted phenomenon, and the more it should be treated as such. It is as though, once medical science has begun to offer a response — however inadequate that response may be — the entire societal context that has helped to shape the public health strategy fades into the background. Once again, it is suggested that people at risk for HIV no longer be treated as autonomous individuals acting in their own self-interest, but rather that they be viewed as recalcitrant and untrustworthy populations who must be coerced into testing and treatment for their own good. While the motives behind this shift — attempting to secure the delivery of HIV-related treatment to the maximum number of infected individuals — may be worthy, those adopting this coercive perspective fail to consider the context of the HIV epidemic.

## B. The Ghettoization of the Epidemic

Although AIDS was initially perceived as a gay disease, and indeed has had an enormously disproportionate effect on the gay male community, public health practitioners and others long expected that, like other epidemics, AIDS would gradually fan out more randomly throughout the population, posing a more appreciable risk to all. To

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42. Arno, *supra* note 10, at 1494.

a great extent, however, the epidemic in the United States has actually remained ghettoized within a small set of groups: men who have sex with men, male injection drug users, and women who either use drugs themselves or are sexual partners of men who do. As AIDS comes to be seen as less of a threat to the general public, coercive responses are likewise less threatening to those who, by and large, shape public policy in this area. It is *they*, not *we*, who will be inconvenienced or whose livelihoods may be jeopardized by mandatory testing or name reporting programs, and the discriminatory consequences that could follow. Furthermore, the communities increasingly affected by AIDS — poor, disenfranchised people of color — are likely to be viewed by the public health traditionalists as less able to be educated and less compliant with voluntary strategies, and hence more demanding of coercive measures.

As AIDS is seen as increasingly ghettoized among disenfranchised populations, the political temptation to use the disease as an opportunity to pursue tangential moral agendas also may increase. As mentioned above, both homosexual behavior and intravenous drug use have been adversely targeted by the federal government, in the form of restrictions on the use of AIDS education dollars to teach these groups how to avoid transmission.<sup>43</sup> Because these groups may be seen as having the potential to “infect” the general public in ways that have nothing to do with HIV, coercive measures may be seen as protecting the public, if not from HIV itself, then from the moral contagion associated with those disproportionately affected by the epidemic.

### C. The Changing Locus of Threat

A corollary to the ghettoization phenomenon has to do with a desire of the “general public” to eliminate even minimal risks that do not so conveniently discriminate by social strata. As the predominant modes of transmission have become less threatening, a compulsion to seek even greater guarantees of safety emerges. Hence, the obsessive quality of the debate over transmission in the health-care setting, and over the appropriateness of testing doctors and patients. If routine dental visits come to be perceived as the predominant HIV risk to white, middle-class, heterosexual individuals, however minimal that risk may be, then public health policy must be driven by the elimination of that risk, whatever damage may be done in the process.

The degree of public and media hysteria over the issue of health-

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43. See *supra* note 19.

care worker-to-patient transmission of HIV would seem to support this thesis. The coverage of this phenomenon has been so utterly out of proportion to its epidemiologic significance — five cases of infection among dental patients,<sup>44</sup> with the route of transmission unknown, and no confirmed infections by surgeons or other health-care practitioners — and to other non-HIV risks to patients in the health-care setting, that it demands explanation. The superficially appealing possibility of isolating and eliminating this threat, however inconsequential it may be, has come to assume paramount importance. The costs (in dollars, lost careers, and quality of health care) of attempting to eradicate worker-to-patient transmission of HIV from the health-care setting are ignored. And the relatively narrow context in which this issue arises plays into a more general sense of HIV as a problem that *can* be isolated and eliminated, if proper steps are taken.

In a similar vein, the public has expressed strong support for immigration restrictions targeting persons with HIV infection<sup>45</sup> — notwithstanding the fact that the rate of infection within the United States is higher than almost anywhere else in the world.<sup>46</sup> Again, this public support reflects a belief that HIV is a problem that people can protect themselves from by segregation from others.

#### D. The Purported Failure of Current Approaches

Another factor undergirding the shift away from voluntarist schemes is the sense that measures tried to date in combatting the HIV epidemic have simply not worked. There is, of course, one naive piece of evidence supporting this analysis: the number of new cases of AIDS continues to climb rapidly in the United States.<sup>47</sup> But that evidence is false and misleading in several critical respects.

First, the incidence of new cases today reflects the incidence of HIV infections that occurred ten to fourteen years ago. Despite the rise in the number of new AIDS cases, there is powerful evidence of massive behavioral change in parts of the gay community beginning in the

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44. See *CDC Recommendations*, *supra* note 3, at 3.

45. On June 2, 1987, the HIV virus was added to the list of "dangerous contagious diseases" that exclude aliens who are afflicted with them from entering the United States. See 42 C.F.R. § 34.2(b)(4) (1990). The others are chancroid, gonorrhea, granuloma inguinale, infectious leprosy, lympho granuloma, venereum, infectious syphilis and active tuberculosis. *Id.* See also Immigration Act of 1990, Pub. L. No. 101-649, § 601, 104 Stat. 4978, 5067 (1990).

46. See, e.g., Thomas C. Quinn, et al., *AIDS in the Americas: a public health priority for the region*, 4 AIDS 709, 709-24 (1990).

47. See *supra* note 40, at —.



early to mid-1980s.<sup>48</sup> This change in behavior is evidenced by enormous reductions in rates of other sexually-transmitted diseases that are more readily manifest and diagnosable. This change, which is largely the product of self-initiated efforts within portions of the gay community to educate its members about transmission risks, supports the theory that providing the right information and support to individuals making voluntary decisions about behavioral change is the most powerful way to reduce transmission.

Second, the conclusion that the strategies implemented to date have not worked assumes that such strategies have been fully tested. In reality, the efforts at HIV prevention education have been half-hearted, have not been well-targeted toward all communities at risk and have not used the kinds of explicit and culturally relevant materials that are most effective. Furthermore, educational efforts to date have often conveyed inaccurate or misleading information (or failed to discuss more realistically effective strategies, such as condom use). Additionally, these efforts have not been supported by programs to sustain behavioral change.

Similarly, the lack of accessible HIV-related medical treatment for many of those at high risk — often because they lack accessible health care of any kind — means that theoretical incentives to seek counseling and testing may indeed be purely theoretical and not available in the real world.

Finally, of course, the “traditional” disease response model has hardly been a resounding success. Other sexually transmitted diseases have not been eliminated, but are rapidly on the increase, despite public health responses that involve case reporting and aggressive contact tracing and treatment. The frustration with our failure to control HIV reflects less the superiority of other models than the reluctance to acknowledge HIV for what it is: an epidemic involving a virus that has a long latency period and that is as yet unsusceptible to attack. We must come to accept that this is an epidemic that is going to be with us for some time, but that we do have the ability to control it if we respond in rational, effective ways.

## VII. The Need to Refocus the Debate

It is, of course, impossible to say what precise combination of the above factors, or perhaps factors altogether different, has resulted in the current retrenchment from the voluntarist response to the epi-

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48. See Warren Winkelstein, et al., *Sexual practices and risk of infection by the human immunodeficiency virus; The San Francisco men's health study*, 257 JAMA 321, 321-25 (1987).

demic. Without aggressive efforts to reframe the current debate, however, the traditional, coercive methodology which appears to be on the ascendancy, in all likelihood, will continue to gain force.

To accomplish a refocussing of attention, and a halt to the erosion in support for the voluntarist consensus, it is necessary to return to the basic premises underlying that consensus, and to demonstrate that these principles are still valid. It remains true today that our best hope of controlling the HIV epidemic lies in long-term, sustainable medical maintenance and behavior change. These goals are achievable only with the active, voluntary cooperation of individuals and communities at risk. While there is a seductive concreteness and tangibility to the notion of widespread, mandatory HIV antibody testing as a public health tool, we must continually ask the question, "Testing toward what end?" Absent means of eradicating the virus or eliminating the ability to pass it on to others, there is simply no valid goal to be achieved by mandatory testing. This being the case, coercive testing regimes will only undercut efforts to secure broad, voluntary compliance necessary to control the spread of AIDS.

Instead of retreating from the voluntarist strategies, we ought to make a concerted commitment to make those strategies fully effective. Developing a structure to deliver HIV-related health care, particularly with regard to early intervention, to infected individuals would create a strong pull into the system. The availability of adequate health care would eliminate the need for coercive measures that force people into testing and treatment. Designing programs to teach, support and sustain long-term behavioral change in all populations at risk would do more to check the spread of the epidemic than massive testing. And respecting the rights of persons at risk for HIV to make their own decisions on these matters will ultimately lead to greater compliance with an effective public health agenda. One can only hope that we will not abandon this approach, which rests, ultimately, upon plain notions of human dignity and independence.